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ABSTRACT

Proceedings of a workshop (Pineville, Louisiana, July 13-14, 1970) on behavior modification programs for deaf-blind children are presented. James Lent discusses the principles of behavior modification and the habilitation of deaf blind children while Pat Aycock utilized case histories to consider shaping behavior of multiply handicapped crib patients. The effectiveness of using light as a motivator and reinforcer is mentioned by Mrs. Aycock. Dr. Thomas looks at certain behavior that can be altered by medical intervention. Dr. Dayan discusses some of the administrative roadblocks encountered when trying to initiate a program for deaf blind children. Throughout the proceedings, the need to call upon diverse resources to bring efficiency to the education of the children is stressed. Jack English summarizes the participant's presentations and draws lines through points brought up by more than one speaker, such as the problem of hesitancy among professionals and others to attempt to work with the children. (CD)

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BEHAVIOR MODIFICATION PROGRAMS FOR DEAF-BLIND CHILDREN

AREA CENTERS FOR DEAF-BLIND CHILDREN

CALLIER Hearing & Speech CENTER

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BEHAVIOR MODIFICATION PROGRAMS FOR DEAF-BLIND CHILDREN

Proceedings of a Workshop Held July 13 & 14, 1970

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Pineville, Louisiana

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Principles of Behavior Modification
And the Habilitation of Deaf-Blind Children

by

James H. Lent, Ph.D.
Director of Research
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The Challenge of the Deaf-Blind

I have worked with the blind and with the deaf, but I have never worked with the deaf-blind. And to tell you the truth, I never wanted to work with them. I just was not sure that I was up to the challenge. Those who work with deaf-blind children are in a position of some people who drive cars. You are a good driver, but if something goes wrong with the car you do not know how to repair it. You do not understand the internal combustion engine and what makes it go. The analogy is that if you are working with the deaf-blind child you also do not know how to repair faulty behavior in that organism. You may repair the car, put in a new engine; you may medically treat the deafness or blindness, but you can not correct the impaired organism. Instead, the challenge lies in trying to raise the level of performance in the deaf-blind person toward a smoothly runing organism.

To do this, it is important to understand the principles of behavior which guide all people whether they are normal or whether they are severely handicapped. These principles of behavior can be a big help in aiding the deaf-blind person become more independent in function. They can lead us out of the wilderness if we are willing to work at it. They can help us help the deaf-blind person even though we may not change the degree of deafness or blindness.

Beyond M&Ms

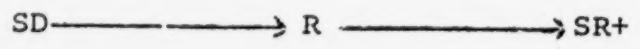
I am going to tell you about something that a lot of you know about and that is a thing called operant conditioning or behavior modification. But I hope to present this in a slightly more helpful way than perhaps you have heard about in the past.

Most people have heard that there is a thing such as operant conditioning. Unfortunately, the image you probably recall is somebody tossing M&Ms to children. Perhaps you say to yourself that if your school could afford enough M&Ms, you could have a program too. So at least you have the notion that reinforcement is somehow possible and could have positive value. The image of someone tossing M&Ms is unfortunate. It has become very popular in the past few years, if you do not have an operant conditioning program then you are nobody.

I have watched these programs across the country come and go, and they do go. The reason they fail is that they are lacking something. All these programs had was M&Ms and the notion that reinforcement was good. There is a great deal more to it than that. Understanding what goes beyond M&Ms and a belief in operant conditioning is the key to building a program which contributes to the habilitation of the impaired person. This is the difficult, sticky part that most people do not want to continue. Too many people who start an operant conditioning program do not want to leave the M&M stage. They are not willing to make the kind of investment in planning and implementation necessary for a successful program. Perhaps what we need to do is to show how a program goes beyond the M&M stage and how the principles of behavior help in developing the sequence of events which the operant conditioning program follows.

The principles of behavior are exceptionally simple. They are the things which guide human learning and, incidentally, animal learning which is where we learned about these principles in the first place. To our shock and amazement the principles of animal learning work exactly the same way with people.

There are three parts to this very simple formula:



One is the SD or discriminative stimulus, which I will discuss later. The R is the response and the SR+ is reinforcement. This simply means that in the presence of a given stimulus of some particular nature, the organism will make an appropriate response and will be rewarded or reinforced for having done so. If you eliminate one part of the formula, it just does not work. If you reverse the order it does not work. This formula accounts for most human learning. The principle is that simple.

Application is not as simple. For a long time, there was concentration on the stimulus end of the formula. The word was passed that if a person did something and you rewarded him for it, he was more likely to do it again. This is true. Therefore, we look at what a kid is doing and we pick a response that he is emitting, some ongoing behavior. We get in there quickly, because immediacy is important, and we reward him in some way for this. If he is in fact reinforced by the reward, he will want to do it again. People tend to do those things that pay off and they tend to stop doing those things that do not pay off.

Suppose the organism does not have a response in his repertoire of behavior that you think he should have? This is why operant conditioning is almost falling out of vogue right now. You have nothing to reinforce. There is no behavior you want to reward. What I am saying is that operant conditioning principles are still valid to elicit types of behavior, but we cannot expect just any stimulus to elicit just any random response. We have to shift to the end of the formula. This is what we must present to the child, a particular kind of stimulus which tells him he should do this rather than something else. In other words, it is setting a stage. Under these conditions this type of response would occur. If we have been fortunate to elicit the response we want and expect, we are lucky. We can motivate him to do it again. All of the hard work is in finding the reinforcement which will elicit the response. This is the teaching end of the business. This is the stimulus input. If you do not know how to arrange this aspect, then how will the child learn what he is to do? If you happen to be bright and have all your sensory capabilities you will probably pick this part of teaching up in some magic fashion. You won't understand it, but that is how we learn. We get a lot of input and somehow we process it. On the other end, we come out with a large number of appropriate responses. This is not true for the child who is disabled. If you are retarded you do not pick up these things as you should. The retarded child does not respond appropriately to stimuli and he may never be reinforced for his responses. The deaf-blind child has at least two major sources of input where stimuli are immediately affected. Most of us learn by looking at things and by hearing things. We use these two senses together to learn most of what we gather through input channels. That is, the mother

points to a chair and says chair. If the child has hearing and vision, he hears chair and sees chair. That is how we learn what "chair" means.

This is not true with the deaf-blind child. So it is back to the stimulus discriminate business, the SD part of the formula. We need to learn how to arrange the stimulus so the child will acquire a response which he does not have. I am going to give you examples of how we work with trainable level retarded children and the severely and educably retarded children, arranging the environment so that the child, in spite of himself, acquires an appropriate repertoire of behavior.

Developing a Schedule

The first step is to carefully decide what response you want from the child. The reason I say it sounds simple and it isn't is that when we enter a new area like this, we tend somehow not to follow a map. We tend to wonder in a forest, picking this tree and that tree and saying that looks like a good one. That will not do. Teaching the deaf-blind child is such a difficult, uphill business that you can not waste your time. You have to decide carefully, beforehand, what are the most critical behaviors for this child to acquire, because you do not have time for the others.

In the project I have been conducting for the past five years at Parsons State School, Parsons, Kansas, this is how we began. What we had was a population of trainable level retarded girls, ages six to 21 years; and they looked like low-level kids, sitting in a dirty low level cottage,

rocking back and forth. We decided beforehand what our major goal was and how we would get to it.

Our major goal was simple: to get them out of the institution and into the community, living a somewhat normal life. To reach this goal, we asked, "What do we need?" We began to break this complex task into manageable specific components. What will be required to get the kid out into the community? To answer this, you write a training program. A training program is a chain of SDs logically arranged. To achieve this chain of SDs, we called upon a relatively new skill of <u>systems analysis</u>. This is simply a way of analyzing a task, breaking it down into its components, arranging it sequentially and presenting them in order of occurance. This is a tremendous help in planning and organizing your activities. To get the child into the community, the following plan might be used:

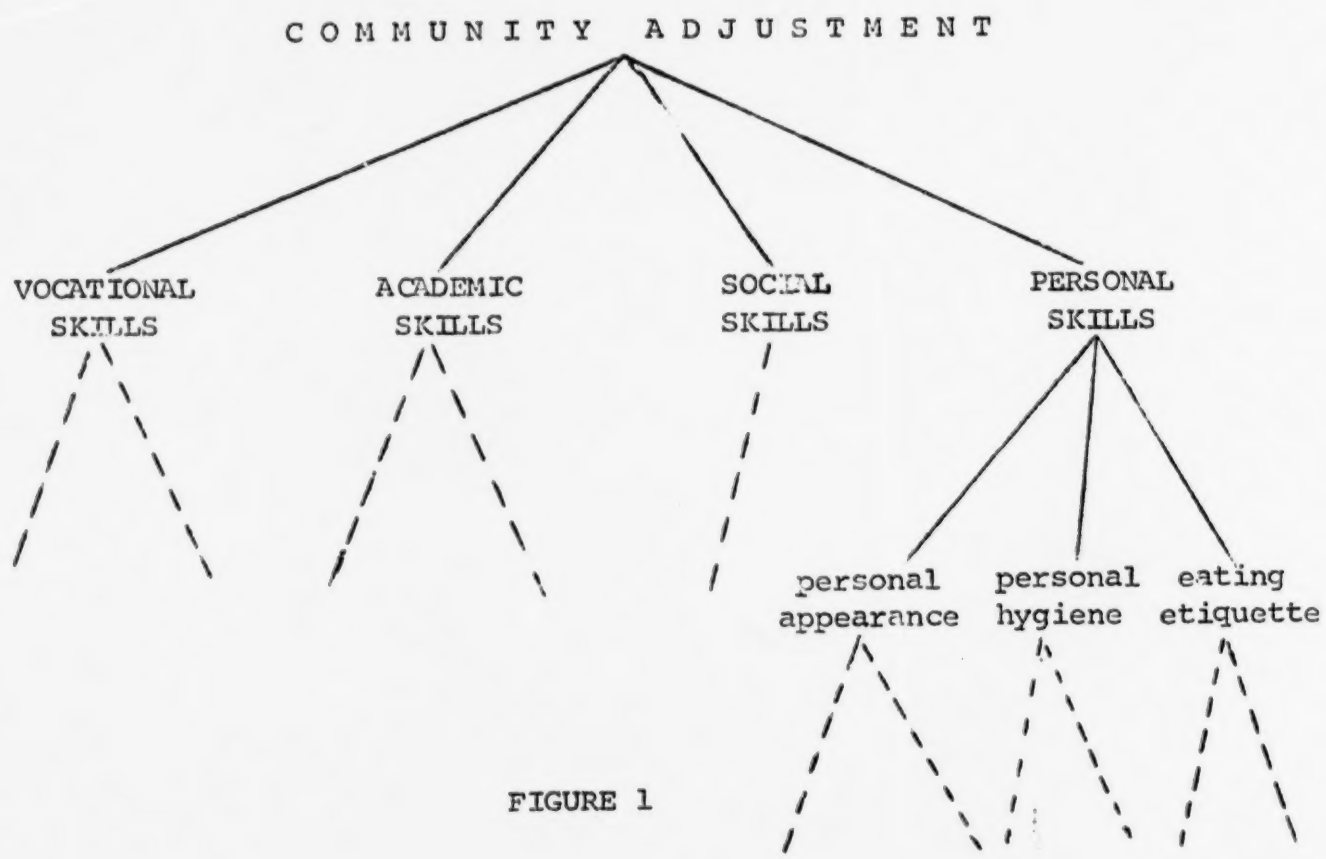


FIGURE 1

In Figure 1, we might start with a vague, fuzzy, ambiguous goal like sheltered community adjustment. That is really what we wanted this group to be able to achieve. The next job was to make the goal less fuzzy, to break it down into more specific components like vocational skills, academic, social and personal skills. These are still a little fuzzy, so you then take each one of these and break them into smaller components. For instance, one way of analyzing personal skills is to list personal appearance, personal hygiene, and eating etiquette.

It might be asked why there was a personal skills catagory in the first place in this sequence. From my point of view, the reason is very simple; it is handicapping to look retarded. If a person looks retarded, people will respond to him as if he were retarded and thus handicapped. If a person smells bad most of the time, this is usually recognized as not being a social help. If a person has poor table manners, these do not help open doors to social acceptance.

Consider the further breakdown of components of social skills. What criteria should be included in this category? The most critical, in my opinion, is responding to authority figures. That will make or break the handicapped child. Some of us can be snotty to authority figures and sometimes get away with it. Some of us can do it, but we have other things going for us. The handicapped child does not. He is completely dependent on knowing how to handle his relationship with authority figures, whoever they may be. Responding to peers is important. It is not as critical as non-verbal social responses, however, we will talk about these later in a better context.

Break down the components of academic skills into further categories. Writing, reading, and some limited forms of quantitative skills are important: telling time, counting, et cetera. Caring for clothes, cleaning house and cooking are basic for girls and needed by most boys. We take each of these and break them down further because they still do not tell us what to do or where to go.

Break down the components of personal skills, personal hygiene, eating etiquette, and all the other components delineated from our big goal. You begin to see what it takes to have a person, any person, be somewhat normalized in appearance and critical aspects of behavior.

Break down the components of social skills. Responding to authority consists of following directions, which in turn consists of being able to remember what people just told you to do, and if you do not understand, being able to ask intelligent questions about what it means. You must also be able to accept criticism. There are non-verbal behaviors which are important. These include gestures, posture, movements, and facial expressions. These are extremely critical; they distinguish you as being funny, different, handicapped, retarded, or whatever kind of person. If you never even opened your mouth, you can distinguish yourself as being this funny sort of person.

Vocational skills include learning to care for clothes, how to sew, iron, use a washer and dryer, clean house, cook, et cetera. Suppose that one of these sub-categories, such as ironing, is delineated under the systems analysis approach. You may see that we are coming closer and closer to a roadmap which tells us how to get the child to the fuzzy goal

we have mentioned. Thus learning to iron is part of a long lattice which is built sequentially from the simplest act to the more complex goal. It is here, however, that simplicity begins to become difficult to achieve.

For the child with an IQ of roughly 25 to 50, you do not teach the child to iron as you learned to iron. You do not get far by having them stand by the ironing board watching you iron and saying to them, now do it this way. What is missing is an intelligent analysis of the act of ironing. What are the components of ironing? Task analysis of ironing indicates that there are certain standard ways which must be learned in order to iron a piece of cloth. The iron must be held in such a manner; the temperature must be set; the cloth must be spread on the ironing board, and so forth in a sequential manner. In other words, there must be a standard way to iron based upon the analysis of the task. Accompanying each of these tasks is a written description which lists the step by step approach to ironing. This allows an efficient method of teaching ironing to this person to be planned before the person begins to learn how to iron. We have decided what the child needs to achieve, which was our major goal. We have decided how to go about teaching this to the child, which is our roadmap or analysis of tasks. We have listed the string of SDs in a proper sequence. Now let us turn our attention to getting the child to move along this lattice.

Toward Activity

Picture, if you will, a typical day in the life of a child at the beginning of our project. Five years ago, there were kids sitting on the floor or in chairs; if they were doing much of anything it was to annoy

other people. Primarily, they just did not have much behavior of any kind. Our first job was to get some activity, some responses. We began systematically to make them active. We put objects in their environment to which they would respond and taught them to use these objects. As they began to interact with the objects, we reinforced them for their activity. We then moved to more complicated activity, not just being active with objects, but being active with other people. To illustrate this sequence, and I make it look simple, the alert research assistant spends part of the day waiting for the child to interact with another person. When this occurs, the research assistant quickly gives the child a token and says, "Good girl." "You and Karen are really playing nicely together." "I am so glad you let her use your materials." Now to do this, we had to set the stage so that the two children would share an activity and receive some type of reward for what they had done that was expected of them. This example skips through the many steps of the program of how we put together a pretty complex series of responses. This is called the floating discrimination program. In other words, how to get yourself dressed in the morning without making it look as if you had dressed at the Salvation Army store.

There are a number of such discriminations needed for a girl to get ready to go out in the morning. The first step, in all of our programs, consists of a pretest. Where is the child now and what is she doing? To document this pretest, we take a motion picture of it. It might be a scene where the model is wearing items of apparel that are appropriate and inappropriate. The child is simply asked to make a judgment, such as here is a stripped skirt and a stripped blouse; do they go together, yes or no.

Of course it can be said that the way people dress is so funny anymore that it is hard to say what goes together. We know that, but we have arbitrarily decided that there are some standards of dress that are appropriate so that we can teach the child how to dress. The girl is wearing shorts, a sports blouse, and high heel shoes. Do these go together? By our standards they do not go together. We could simply record this response. This is an example of the test we would give, and they tell you what needs to be taught.

We know, at this point, what the child knows about a certain subject. We know what we need to teach. Where do you start to teach and where do you go next? We could start with the child learning to discriminate between materials, fabrics, and color by using samples. The next step after that will be to have the girls, members of the class in clothing discrimination, go in and dress up and let the other members of the group judge if their dress is appropriate or not. Members of the group giggle and point and comment on what goes together and what does not. They are role playing a variety of things like this, only there is sequential planning behind the introduction of tasks to be learned.

There is the ironing program, a walking program---most important to teach the girls to move with ease and not give the appearance of being slow or dull. The problem we have had with the walking program is that the girls do not generalize; they walk like ladies in the class, but not when they are out of the classroom.

There is a hair care program. This is probably the most dramatic and effective program that we have. Of all the things you can do to normalize

a person's appearance is to style the hair appropriately, comb and set it for that person. We have a beautician from the community who does it for the girls in the beginning, then we pretest the girls and send them out to take better care of their hair. This is the underlying goal of all of the programs, getting the person to do for himself.

There is the showering program. This is one where the SDs come to the child in the form of words and music. They set the stage, guide, and control the child's showering behavior. We would start with a dry run with a research assistant showing them how to listen to the music and follow the instructions. Then the girls listen to the music while in a shower and follow the instructions to wash their knees, arms, or ears. While the music is playing, the girls are showering for the first time in their lives appropriately and easily. This is one aspect of management of social behavior.

To carry over the idea of rewarding good behavior, there are charts in the cottage. These simply mean that when things are pretty stable in the cottage and there are no big troubles, you can do something as simple as saying, okey kid if you go all day long without goofing, you are a good girl and I will give you a star and you put it on your chart yourself, and we give a little bonus like two pennies. If the child has seven stars in a row, then she is really a good girl and she gets a gold star and a bonus in pennies. This is to point out that we have positive and negative controls for social behavior. This is a good girl----this is a bad girl. If a girl is bad, she is timed out for reinforcement, such as standing in a square contemplating the evils of her ways; this withholds social

reinforcement. She is ostracized for five minutes. Now if she wants to go along with the group she can get out of the square and back into the cottage world and she is still a good girl eligible for a star and a penny. If she will not go along, then she can go into the isolation room for 15 minutes. She is responsible for her behavior and can select alternatives which she is to follow in her cottage setting.

The eating program teaches manners to the girls, one or two at a time in the back of the cottage, not in the cafeteria. They learn how to eat without embarassing themselves. They they go to the dining room and if they can demonstrate that they have learned to eat, that is if they can generalize, they get to join a group downtown at a real restaurant, for a real meal, and a big evening.

There is an experimental classroom where the children learn academic skills, such as reading as high as perhaps the second grade level. There is vocational training, learning to clean a house, work in the cafeteria, or take care of clothing.

These are the training programs with stimulus input to get them to respond, but we need to motivate children to do the things we want them to do. We want them to do again and again, and eventually do these things on their own. To motivate them to move toward doing things on their own, we start out rewarding them with immediate reinforcement for desired behavior with a consumable goodie. We only use the M&Ms in our program for perhaps two or three days. What we do is quickly to condition the children to a generalized reinforcement, such as money is to you or me. In itself it is

of no value, but it can be exchanged for a wide variety of the good things in life.

The transition from immediate rewards to deferred rewards can be simple. An illustration of this with low-level children would be for the research assistant to reward several minutes of good behavior with a little plastic disk rather than an M&M. She quickly says that she would like to trade and holds out an M&M. She gets the token back and the child gets the M&M. The M&M is usually a quick trade for the plastic token. Then we stretch the time between exchange of the token for the backup goodie. Pretty soon the token has acquired reinforcing property and you can eventually save them for long periods of time, and trade them for almost anything. There is a little store for use by children in the cottage. What we want them to do is to start buying things that will normalize them; we encourage them to buy things like nail polish, a new bra, under arm deodorant, or something like this. Pretty soon these things become rewarding to them and they are spending their money to get them; they do things to get the money that we wanted them to do in the beginning.

For one group of children, English halfpennies are used to get the children to put them in a penny bank. The banks are generalized reinforcers with plexiglass fronts. The child drops the pennies in the slot and they can see but they cannot get to them unless the aide opens the bank for them. The research assistant watches to see when one of the girls does something to help another person. She says, "Good girl, Valerie, that was sure nice of you to help her with that top button." The discriminative stimulus is what? The words the research assistant used. Those are the

conditions under which the child just standing there unbuttoned becomes a discriminative stimulus for the response of helping and if the child helps another person, the child is paid a halfpenny. Pretty soon you do not even have to give the token for helping others. Phyllis will say thank you to Valerie and that is a big pay off and that may be even better than tokens. Pretty soon they are being controlled by their environment, just as you or I am controlled by our environment.

Beyond the token stage, where halfpennies are given for good deeds, there may be an even higher stage. In this stage, the amounts of credit earned are kept in the bankbook and the child saves for privileges and money to buy things. The highest reinforcement system we have in the cottage is where there are no tokens but you are earning real money, in small amounts, and the child operates on a pay-as-you-go system. This is one of the final stages for being able to get out of the institutional setting, that is, being able to manage one's own behavior. The child learns that it is a good life, if you keep your nose clean, but if you do not have the money for something then you do not get it. Without money, first the luxuries and then the necessities have to go, if there is not enough money for a bed, then sleep on the floor. There may not be enough money for a meal ticket, so the child eats an uninteresting meal, nourishing, but uninteresting. That is the way the real world goes.

Relating to the Deaf-Blind Child

There are two difficult tasks involved in the behavior shaping program. The first difficulty is in writing a training program successfully.

The other is in managing a reinforcement system. They call for hard work and imagination; but if you put them together, if you are willing to make the investment, a behavior shaping program will be highly successful. With children who acquire new, appropriate responses which let them begin to act like people rather than like things, the framework of the behavior modification program is begun. You must make the decisions as to how to move the child along the lattice.

How does this relate to the deaf-blind child? Perhaps the first challenge which is issued by this review of behavior modification techniques is that the goals for deaf-blind children may have to be re-thought. There needs to be a list of the behaviors which you want from the deaf-blind child. Put them in the order of development and importance. From this, take only the most critical responses; leave out all the others. Make sure that the first things to be taught are listed first, the sequential arrangement of tasks is central to succeeding with the program. Once you have picked out a behavior, a program must be written; you must have a plan. There is too much work in classrooms, clinics, and broom closets where the teacher goes into the session without knowing exactly what is to be done. The discriminative stimuli are first written for the teacher. The teacher chains that together so that a system is mapped out as to exactly what the child is to do.

Writing the training program consists of taking the SDs and analyzing the task carefully, listing each component. This is writing a preliminary description of the steps. This should be tried again and again and revised again and again with the underlying thought being that it is not

the child's fault if learning is not taking place; it is the program's fault. You will see that this is literally true as you write and revise the sequential tasks.

Getting the child to do something which you have decided he should do is the goal of the program. The program you write should be revised until it produces these results. You, also, need to be reinforced for your efforts in teaching the child. It is when the child does what you have decided he should do that you get your big pay off. Choose something very simple, such as getting the child to orient to a stimulus you have presented. That is getting the child to attend, to pay attention. If your first goal is to get the child's attention, you have succeeded. If you get it you are a winner. Once you have the child's attention you may decide that a valuable first response would be simply turning his body. If you can get the child to do this, you have again succeeded. You can go on from here to new successes, but you need the first experience of getting him to do just what you have decided he should do. This is not always an easy accomplishment. The deaf-blind children ordinarily do exactly what it is they have decided to do. Guess who is in control when we are working with the deaf-blind child, or the autistic child or the profoundly retarded child? It is not us. Usually they are in charge.

There are special problems you will encounter in working with the deaf-blind child. These usually are very vulnerable to behavior shaping techniques. The two major inputs, hearing and vision, are impaired; but how does the child use residual auditory and visual channels to see and hear what is going on? How can a program be written to aid in better

utilizing the eyes and ears? There are also other sensory channels of input. People tend to be terribly imaginative about the use of senses that do remain. You can reinforce behaviors through tactile modes, touching the child or having the child touch something. There is the sense of smell which may be used with the child learning to discriminate through odors. We have all been pleased and reinforced by odors, so can the deaf-blind children. You may give the stimulus input on one channel, say by touch, and reinforce through another channel, as in smell, or taste, or residual auditory or visual channels. Of course the old standby reinforcer is love. Close, warm contact with the body is probably the best reinforcer for these children, but some children will not respond to being loved or even picked up or patted. They need to be taught that this is a big deal.

Another thing that has not been systematically used or imaginatively applied as a teaching tool for these children is punishment. Most of us are afraid of punishment, and well we should be if we know exactly what we are doing. There are all kinds of punishment which may be used, and somewhere in the process punishment must be used. Children need to discriminate those things which they can do without being punished and those things which they can not do without being punished. Punishment can consist of deprivation, going without something you have decided the child seems to value. I think the child progresses more quickly and efficiently if we can systematically pair from positive reinforcement with strong negative reinforcement.

Relating to the Teacher

There is one final segment which is most difficult to achieve. This is the need to discipline yourself, as the teacher, when you are working with these techniques and with these children. It takes some discipline for most of us to behave in ways that may seem punishing to the child. Using the framework of operant conditioning vocabulary, what we usually do is to dispense reinforcement noncontingently, that is, we reinforce regardless of what the child is doing. We have been taught, in some strange way, that you have to love the children a lot. We often interpret this to mean that we have to love them under all conditions, at all times. There are teachers with the philosophy that somehow the power of magic will heal if I just hand in there and never quit loving. This particular attitude has held back education for many years. Love is the most powerful tool we have if we use it contingently; it is the most destructive tool we have if it is used noncontingently. This is where the discipline comes into play; the teacher must be able to behave contingently. Withholding your attention and affection in the presence of an inappropriate response is very difficult for some of us to learn. On the other hand, it is almost as difficult to be able to be alert to appropriate behavior and to reinforce it immediately with attention and affection.

It takes discipline to behave in a systematic fashion with these techniques; but you see, that is the secret. There is very little new about operant conditioning, it is a common sense system applied with discipline in a systematic manner.

The need for discipline carries over into the writing of a program; do not proceed without a plan. Even more serious, do not think that you can succeed without writing out a planned program. It will not work. A planless session with a child is a waste of time for the teacher and the child. There are no easy substitutes for written plans, they speed the way to achieving the goals of the behavior modification program.

SHAPING BEHAVIOR OF DEAF-BLIND CRIB PATIENTS

by

Pat Aycock
Pinecrest State School

The focus of this presentation is to tell about the reinforcement program for deaf-blind children at the Pinecrest State School, what we are doing with these deaf-blind children, why we are doing it, and where we are going. I feel that I quickly can answer the last statement, where we are going, by saying that we are changing behaviors in these deaf-blind children. The progress is steady, if slow.

The Pinecrest Program for Deaf-Blind Children

The superintendent, Mr. Coates Stuckey, is always on the lookout for ways to improve the lives of residents of the Pinecrest State School. In the last part of 1969 he asked me if I would be interested in working with deaf-blind children. I had previously worked with profoundly retarded children in an operant conditioning program and looked forward to working with these deaf-blind children in a behavior shaping program. We began the program in February, 1970 with three deaf-blind children who did not walk and spent most of their time in cribs. These children were dependent upon others for almost everything. I work with these children five days a week and began by observing these children in their cribs. Through observation of the child, I tried to establish a base-line as to where the child was as far as development and responsiveness was concerned.

The first child, who we will call L.L., is six years old. He spent most of his day lying in the crib, rocking back and forth. Occasionally he would wet his fingers with saliva and wave the fingers in front of his face. He had a thing with light; it seemed to motivate him, and I felt that was a positive response. He was fed lying down and food was more or less poured down him. He did not seem to get any pleasure from eating. His clothes were tied on him since he would remove them if he could. He whined constantly. He could stand. He seemed to like to stand by holding on to things for security purposes. I decided that the first thing to do was to get him out of bed. I got him to stand with support and worked with him to learn to stand alone. I tried to reinforce with foods, ice cream, Cokes, M&Ms, but he did not respond to this. You would think that he would like this, but he did not. So, I turned to other types of reinforcers: a velvet pillow, a bean bag, anything I thought might be pleasant to touch. He would just push them to the side. I tried perfume, different fragrances. This did not seem to encourage him. So, I relied on the light as a reinforcer.

My second goal was to establish a level of rapport with him. He did not like to be touched and would push me away when I came near him. I wanted him to respond to something I was doing, so I took him out into a brightly lighted hallway. I held his hand and he could stand in the hall, against the wall. He would hold on to my hand tightly and we would walk across the corridor. His reward was to play with the glass in the windows; he would pat the glass, sometimes real hard. After he had patted the glass in the window, we would turn (I had to

turn him since he did not turn independently.) and go back across the corridor. We did this walking and patting over and over until he was at ease walking and holding my hand.

One observation I made during this time was that everybody I would pass in the hall would say, "Give me a cookie. Give me a cookie." I guess that they thought that I had to give him a tangible reinforcer for walking. That is what they thought I was doing to get him to do these things, little did they know that a cookie was not meaningful to him. What I wanted from him was some types of responses and what I wanted to do for him was to stimulate him. He was typical of the children who were crib patients; his world was his crib. I wanted to provide some type of stimulation to expand their world and their responses to their environment.

The next child, S.W., is a five year old girl who is non-ambulatory. She was lying in the bed in a frog-like position. She did not move; she never cried or made noises; she seemed to be a lifeless thing. My observation of her was that she just laid there and did nothing. When they fed her, they had a pillow under her back, one hand tied, and would force her to eat. They would hold a spoon to the back of her tongue until she would swallow. Sometimes they would hold her nose to make her swallow.

My first goal was to try to get her to eat without being forced to do so. I knew that I could not use food as a reinforcer since she did not like it. I also found that she did not like to touch things or to be touched.

I used getting her out of the bed as a motivational device. I would sit with her in the room and attempt to feed her. She began to respond to this, when she was out of the bed and now she is eating, that is she still has to be fed, but she will accept the food and she will swallow it. Even the aide can feed her now.

Another child, J.C., is a girl, totally deaf and totally blind, who also has a clubbed foot. She did not want to try anything when I observed her. If she met a stranger, she would push him away; she did not want to be touched or handled. She whined and screamed and kicked.

I put her in a walker in the room and placed a velvet pillow beside her. She did not like the velvet pillow and would push it away. I would replace it next to her and she would push it away again. I felt that with her pushing I was at least getting some type of response. She was reacting to the pillow, even though she was negatively reacting to it by pushing it away. So I would put it there and she would push it away and I would put it back and she would push it, and we went on like this. She finally scooted out of the walker onto the floor one day; I threw the pillow down and she reached for it. She grabbed the pillow and put it under her because the floor was cold. I knew then that we could work in an operant conditioning program with this severely involved girl, even though we would have to take a long route in getting her to respond.

There were other problems, and I had to face them as they arose. There is always a way to get the child to respond, if you will use the

ideas that you have and understand the situation. I decided that I knew what was best for them and that they were going to do what I thought was best. I chose things that would be rewarding to them, such as walking, chewing gum, eating, holding the velvet pillow. Of course, I set the pattern for them. I would make them do things over and over until it became rewarding to them.

These children were all negative about being touched. Now they like to be touched. They have acquired a taste for food which they did not have before. Their sense of smell seems to have been discovered and they now respond to odors.

All of these children are deaf and blind. Two of them have light perception. The second child I mentioned, the little girl, S.W., was diagnosed as being deaf. We have since decided that she has some hearing. All of these children exhibited a withdrawn type of behavior which may have been due to the lack of interaction and stimulation for them to relate more directly with their environment. In the beginning of our sessions, S.W. did not respond to sounds; she did not respond to anything in fact. Now she is beginning to imitate gross sounds when I make them. This child was completely helpless when we started; her legs would not go together, she kept them in the frog position. I used passive exercises and now she is moving her arms and legs. It is quite remarkable. She sits up to eat, of course we have to hold her, but she is eating on her own without being force fed.

One of the stimulation activities I tried with S.W. was to put her in the bath tub. She loves the water. I would let her play in the

water and I would splash her and she began to kick. I asked the podiatrician at the school if he would prescribe a whirlpool bath for her. She is now taking the whirlpool baths and screams, kicks and squeals with delight when she is in the water.

Let me talk a minute about breaking down the tasks into component parts. I wanted to teach these children to eat. So, I began to teach this by breaking down eating into its parts. The food needs to be brought to the mouth, the mouth opens, the food is taken into the mouth, it is chewed and swallowed. Then the task is repeated. I knew that for the time being, I would bring the food to the mouth. So I needed to concentrate on getting them to open their mouth, chew, and swallow. Chewing seemed to be the key part that I would have to hit. Really, to enjoy food, you have to chew it.

I started with two pieces of chewing gum. The gum was softened in warm water and then put into their mouth. Of course I did all of the steps of getting the chewing gum to the mouth and getting the mouth open. After they got a taste of the chewing gum, it was not too hard to get them to respond. They would keep the gum in their mouth, but not chew. So I would mash down on their jaws and then push the gum to the other side of their mouth with my finger and push down again on their jaws. Now two of the three children are chewing and the other chews occasionally. Some people were concerned that the children would swallow the chewing gum or get choked. That is one reason I used two pieces at a time; it made a larger quantity and harder to chew. If the child were to choke on the gum, I could reach in with my fingers and remove it, but this was not a problem.

I have confidence in this method of training. It really works if you break everything down into small easy-to-learn steps, by having the child learn the primary steps and by doing them over and over again until they learn it. As soon as they learn the first step, go to the next one, and soon the child will be able to move along the sequence of steps and will be able to accomplish the task.

You set your goals; such as with S.W., my goal was to get her to walk. This means moving from the frog-like position in a crib to walking. Everybody laughs at me about this goal, but I believe that I can get her there. When I first started with these kids, one of the aides said that I would spoil them. She did not mean it maliciously. I know that sometimes when I was rocking J.C. and would put her back in her bed she would cry. Some people said I was mean to cause her to cry, but I would cry too if I spent 24 hours a day in a bed. It was enough to make you cry. Part of our program to get her out of the bed was to teach her to rock in the rocking chair. At first she would slip out of the chair and I would put her back in the chair. She would slip out again and I would put her back. If she would quiet down I would reach over and pat her. Then she would slip out again. The aide was observing this and she shook her head and I said that I was teaching her that rocking in the chair was pleasant. The aide felt that there should be some better way, but I pointed out that J.C. would soon learn. I said that at least I felt that we owed them the opportunity to try different things. The aide said that she did not know whether we should bother with training them or not. She did not mean it the way

it sounded to me, I am sure, but she thought that we were being mean to the child to make J.C. sit in the chair or to have the pillow placed next to J.C. when she did not want it. Now, J.C. rocks in the chair and enjoys the experience. This has changed the aide's attitude. The aide now thinks that these deaf-blind children can be helped. This was our second major goal. Our first was to try to get these deaf-blind children to respond to their environment, to stimulate them. Our second goal was to change attitudes of staff members toward these deaf-blind children. Our program has been in effect since February, 1970 and we have begun to attain these goals.

Discussion

Question: Are you finding with these deaf-blind children that after the initial response the second, third and fourth response you build on, that responses come easier and faster?

Answer: They do. They definitely do. You have to establish a relationship with these children, then it becomes easier to move from one thing to another. One of the hardest things to do is to get them out of their little world. Each new setting is threatening to them and they resist it by whining or crying.

MEDICAL ASPECTS OF DEAF-BLIND CHILDREN

A FIVE YEAR DIARY

by

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During my training in pediatric neurology, in 1964, I was assigned to do neurological examinations of post-rubella babies referred to the University of Oklahoma Medical Center. This was how I became involved with deaf-blind children in Oklahoma.

The babies we saw were not born at the O. U. Medical Center, but were usually referred to us early in life, especially if they had cardiac problems. Some of them came to us as early as one month of age. Since we knew the rubella epidemic was then moving from the east coast to the west coast, it was apparent that we were going to see a number of these babies. Therefore, a team of specialists, including a pediatric cardiologist, a pediatric neurologist, general pediatricians, ophthalmologists, and otologists, was established. The staff and resources of the Oklahoma University Medical Center were also available to provide us with further special talents. We saw about 20 deaf-blind children. We knew that there were more of these babies in Oklahoma who we would be seeing later, but we were concerned at this time with those children who had serious medical problems very early in life.

There were two life threatening situations which occurred very early for these babies: heart problems and blood problems. It is interesting that the epidemic varied from region to region, both in the way it affected the babies and in the strength of the virus. We did not have, for instance, a high rate of babies dying in Oklahoma City. Our population also did not seem to have the blood problems which our populations of post-rubella children had.

As soon as possible after the babies' heart condition was stable, I did a neurological examination. Several things were apparent from the very beginning. Some of them, we thought, were blind, while others did not seem to have visual problems. Cataracts were not always apparent although there were other eye conditions: glaucoma and chorioretinitis. They all seemed to be deaf.

There were two outstanding behavioral characteristics in this group of babies. One was the intense hyperactivity which showed up as early as one month of age, up to six months of age. This was a frenzy of activity on the part of the child. With the passage of time, this activity tended to decrease in intensity. The oldest baby we examined was nine months of age and this hyperactivity was not evident at that time. The other outstanding behavioral characteristic was the absolute addiction to light of the children with visual problems. These babies tried very hard to find light sources. Even before they could turn over, when all they could do was posture their head and their trunk, they would do things that you really did not know babies of this age could do, in order to turn their head to a light source. This

characteristic was definitely present from the very beginning in these children.

One other remarkable characteristic seems to be that, while these babies were not premature by gestation, they were small in size. I noticed that the babies' head size was small. The fontanels were not tense or tight, they did not seem to have an increased pressure, but they were wide open. This condition persisted for a long while and although the fontanels did eventually close, they did so later than what is expected of normal babies. The sutures, except for the front one being somewhat more open than one would expect, were otherwise normal. They did not close early nor did they stay open, except for the fontanels. The postural fontanel tended to remain open longer than usual, but it was not as marked as the anterior fontanel.

Some of these babies also had what might be called a partial first arch syndrome. That is, these babies did not have cleft palates, but the palates were very high, very narrow. The lower jaw was short, even shorter than a newborn's jaw should be. The ears were not malformed, but the cartilage was very, very soft. Occasionally, the cartilage would be more soft on one ear than on the other. I have not been able to tell whether this was related to the child's hearing. I was not able to correlate this external anomaly with hearing, but their ears do remain softer than you would expect. I do not know what this means except that this is a mild developmental abnormality.

Some, not all, of the babies had changes in muscle tone. Some were hypertonic, others hypotonic. I had come to the conclusion that a

floppy baby, one whose tone was decreased, was probably worse off than the baby who was hypertonic. This population seems to support this conclusion. The ones who were hypertonic very early in life have been able to reach developmental milestones and, in general, have done better than the ones who were floppy babies from the start.

There were also some bone changes, which I think was first picked up by the group in Houston. We did not see so much of this in our population, perhaps we did not look for it soon enough.

There were eye problems in most of this population. Cataracts were found in some of them at birth. Later on, some children developed glaucoma and some showed the effects of chorioretinitis. These visual defects were not always bilateral.

Another interesting thing we found, and I do not know what it means, is that all of these babies were born with a brown spot in their umbilicus, that is when their cord dropped off. This was first pointed out to me by Dr. Murdina Desmond of Baylor Medical Center, Houston. I asked the people specializing in infectious diseases at the University of Oklahoma Medical Center to help me find what this meant. I wondered if this might be a sign indicating rubella, but later I found the same type of brown spot on babies who had cytomegalic inclusion virus. I can not even say that the brown spot is related to viral infections since I have found the brown spot in babies with toxoplasmosis. Perhaps this does not have significant meaning in relation to the infectious process. I have observed that this brown spot fades by the time the baby is three years old.

We studied these children with electroencephalograms, not because any of them were having seizures, but to establish our baseline information. We got EEG results on monthly intervals until they were nine months old, and then every three months until they were two years old, and then each year. We saw, in all of our babies except one, some changes in the brain wave tracings on the electroencephalogram. These could certainly have been compatible with seizure disorders as far as looking at the EEG tracings. I had quite a time deciding whether or not to medicate these babies. I decided to observe these children a little longer before medicating because we did not know if these children would have seizures. It happened that it was apparently the right decision, because only three of these children, who are now six years old, had to be placed on anticonvulsant medication. The others still show abnormal EEGs, not so much as seizure type discharges as there are indications of change in rhythm of the brain waves. On those children who have real visual problems, the occipital area tracings show changes similar to other babies who are blind but not post-rubella, so this seems non-specific as far as this population is concerned.

An interesting finding in the EEG studies was the 14 and 6 per second readings were not occurring in the temporal lobe areas but it was occurring up front. We never knew what that was; it went away, but it was there.

Another difficulty with this population of post-rubella babies was nutrition. I think this is a general aspect which is found in this population. Some of these children have difficulty chewing. They seem to be very sensitive to the texture and temperature of foods.

These children have had surgery for various medical problems. Most of them have had cataracts and have had surgery for them. Many of the little boys have had hernia repairs. We have had one child who has nephrosis. I have no idea if he would have had kidney involvement if he had not had other problems. It is difficult to relate these conditions directly to the rubella virus. These children may have illnesses just as any other child may have. However, I have been concerned with these other types of problems from the very beginning. My concern centers on how other problems may effect the child using what was left after the rubella syndrome and how we could help the child use what he has in the way of abilities.

An example of this is in trying to define the hearing problem. We knew that many of these children had visual problems, perhaps that they were blind. We tried all sorts of ways to test their hearing, to see if they were also auditorally impaired. There seemed to be no way that we could indicate in the usual way that the child could hear. We tried to elicit a startle response to sudden noise, but the children did not respond. We tried some of the instruments devised to test hearing in the newborn, but they did not work. As it turned out, many were not deaf but had some residual hearing; but they appeared deaf in the beginning and we could not tell from all the things we had to assess hearing how much they could hear.

My concern in this instance was about the tremendous sensory isolation that these children had. As a pediatric neurologist interested in developmental aspects, I could see that this isolation

was terrible not only in the newborn phase, when we could not tell what was wrong, but also that it contributed to further delay in development as the child grew older.

As soon as the baby is born, sensory inputs from the ears and eyes start. Unless they get certain sensory inputs in the first year of life, they become developmentally delayed. I began to wonder what we could do to reach these young children, because I could see problems such as the child communicating with his mother, or learning from his environment. One of the things I thought was that this hyperactivity in the first months of life was an attempt to increase sensory input into their nervous system. Perhaps they were trying to get the input going and since the input did not come through the normal channels, the eyes and ears, they had to try other ways of sensory stimulation, such as hyperactivity. I do not know why the hyperactivity decreased, perhaps they found out it was unsatisfactory or the hyperactivity furnished them with all the sensory stimulation that it could and then was not meaningful any more. I do know that they were hyperactive in the early months of life and that it decreased as the children became older.

We began to try to work with some of the parents of these deaf-blind children. Our first goal was to stabilize the medical problems and then try to help the parents understand the child and the condition. Some of the children required cardiac medication. Most of the surgery was postponed until later, so the children were first stabilized on medication before surgery could correct the cardiac problems.

We began to work with one mother to try to develop some type of signal system between her and the child, which was not very imaginative, I have to admit. But this system tried to get the mother to communicate to the child in some meaningful way. We did not think that the child heard, or that he could see, and we knew that he had muscle tone changes. We told her to signal the child when she was going to feed him. She had a signal for this just by touch. She had a signal for when she was going to change his diaper. It was felt that this gave some type of sensation to the child, even though it was not to the degree that we would have wanted. This mother would not, or could not do this. It may have been her personality or a defect in the communication/ sensation concept, but the child was not receiving what he needed. The mother was too discouraged.

I was a faculty member in pediatric neurology at the time and was not associated formally with the Child Study Center. I asked the director of the Child Study Center if he could find some way to take this child into the Center. I wanted someone to work with the child and with the mother, because the child was so sensorially isolated I knew that something had to be done soon. By this time, the baby was six months old. The director agreed to do this. He had a marvelous teacher at the Center who was a speech pathologist as well as being trained in working with children who had learning disorders and being trained in Montessori methods. She started working with the child and with the mother. I think that she got hooked on working with deaf-blind children in this instance. I should mention that this initial program was

sponsored by the Child Study Center and that other monies were not available for this program. Even so, the Center started taking in other deaf-blind babies, all of them, I believe, under one year of age.

Two years ago, money became available through the joint efforts of the Oklahoma Education Agency. The Oklahoma Education Agency, Department of Special Education, worked out an agreement with the Oklahoma City Public Schools to establish a nursery school for deaf-blind children which would be housed in the Child Study Center of the Oklahoma Medical Center. This year, further help in financing this program will come from the four state cooperative project to develop services to deaf-blind children. We are planning to continue primary grade programs through the cooperative project, with the programs hopefully housed in public schools in the city.

There were many frustrations. No one had any experience with deaf-blind children who were this young. In an attempt to try to find out what we should do, we had some people from Perkins School for the Blind come down to Oklahoma City. They had the same problem, in that they did not know what to do with a six month old or nine month old baby. Someone was visiting the Medical Center from England who had worked with deaf-blind children older than our population. We had him come to the Child Study Center and he evaluated the children and we had the same old problem, no one had any experience with children this age who were so involved. This was our problem everywhere we turned.

We tried to get speech and hearing to tell us whether these babies could hear and they ran, because they had not had experience

with babies. They did not seem to know what to do with babies six months of age or younger. They will take them this young now and try to find out about hearing, but it took a little attitude change. I am not saying this in any bad sense at all. You know medical students are usually awed when they go on the pediatric ward, because, you see, they think that children are really breakable. This was the sort of thing that we ran into; people just did not know what to do at this age for these children. Again, I am not knocking those who did not know what to do, it is just that they really had not had to face that problem before. I have said it before, and I will repeat it: when we started, those babies taught us more than we were really doing for them.

One of the positive things that this program did do was to bring mothers in for sessions. This helped them learn about the child. Another positive aspect is that there must have been some things done correctly, because none of these children are in state schools for mentally retarded at this time. In fact, the program is a classroom for the Oklahoma City Public School system.

The staff for the program now consists of a very fine teacher and a social worker who has efficiently organized a parent discussion group. Volunteers play an important part of the program with each child having a volunteer assigned to do individual work each day. The teacher works with the volunteers before the children come to class, setting up activities based upon observations made by the volunteers and the teacher. At the end of the class day, the volunteers and the teacher again meet to discuss what the children have done and what

types of activities are needed to help the children. This ongoing discussion between volunteers and teacher has helped make the volunteer program meaningful for all those concerned. The medical team is also available for consultation and re-evaluations which are conducted on a routine basis.

One of the big things that we had to do was to involve the parents in a more positive role in the habilitation of the child. Our minimal hope is to give moral support to the parents. We have found that the sessions where mothers discuss the daily encounters of their child with life are important. The social worker conducts the sessions, but the mothers find strength when they sit down with other mothers and talk. If they are low that session, they can cuss the general situation, they give each other support.

The mothers are also responsible for presenting programs in these sessions. They have asked me to speak to them once or twice a year. I find that the invariable question during these presentations is: What is going to happen to my baby? Other programs present films or materials about deaf-blind children. They talk about the home training programs which have been established for each child.

There's one other thing I want to mention. On February 1, 1970, Oklahoma had a Rubella Sunday. A tremendous job was done by the state Medical Association. We cooperated to the extent that our babies were shown on T.V. and some of the parents were interviewed for the program. There was a tremendous response to Rub Out Rubella Sunday. At that time

we vaccinated approximately 50% of the susceptible population. We now feel we should not have another rubella epidemic in Oklahoma because much of our population of susceptible age children have been immunized.

Now, I would like to share with you the developmental histories of four of the children in our program. The developmental aspects of these deaf-blind children are of interest to me. I would like to share some of these observations of development with you.

CASE: John, male, program begun in 1966

Developmental Observations:

11 months	Places weight on forearms
12 months	Pull to sit, complete head lag when held sitting with rounded back, hands to midline, pull clothing over head in play, over-reaches for objects, plays with rattle placed in hand, sits tripod
13 months	Sits supported in high chair, sits momentarily on floor without support
13-14 months	Makes sounds but imitation unlikely
14 months	Creeps, sole of foot intermittently on floor
14½ months	Weight on hands with arms extended, chest on table
15 months	Goes backward in attempt to crawl
15-16 months	Stands holding onto furniture, pulls to stand
16 months	Walks like bear
17-18 months	Laughs loud

Commentary: This child was staying with great-grandmother while both parents worked. It seemed evident that great-grandmother provided excellent schedule and lots of stimulation for the child. He appeared to see objects at a distance of more than two feet. He especially showed pleasure in the lights of the Christmas tree. He seemed to use the right eye more than the left. In initial evaluation, he was cooing and frequently used the "mmmm, mmmm, and uh" sounds. Most of his time was spent on his back receiving sensory stimulous through activities with the hands. His left hand was placed with the back toward the face and he would wave his in front of his eyes, at the same time, touching the thumb of his left hand to the thumb of his right hand.

At this time, he exhibited poor head control. When placed in a sitting position, he would be seen to throw his head back. On his stomach, he would raise his head quite high with his arms straight, supporting the weight on his body. He was not, at this time, sitting by himself.

He rolled from front to back and from back to front. He was seen to stimulate himself by taking his left hand and slapping it against his left leg. The grandmother felt at this time that he would raise his hands when he wanted to be picked up.

At a little more than a year, the boy was sticking objects in his mouth and keeping them there for a long time. He showed interest in water at this time.

In February, 1966, this child could assume a sitting position if he could hold on to another person. He appeared to hear sounds according to his grandmother and he responded to his grandmother's voice. He was working his tongue in his mouth most of the time during this period. The grandmother felt that the boy knew when he was going to get his diaper changed; when she would start to change the diaper, she would put a newspaper under him. He seemed to anticipate that this meant that he was to have his diaper changed.

He was beginning to thrust his thumb into his eye. His sitting balance toward the end of February, 1966 seemed to be improved. At this time, he was scooting around on his back and assumed a position of balancing on top of his head and feet, with his face up. He was showing preference with objects which made a noise. His grandmother stated that he mimicked "uh-huh" after she had repeated it to him several times.

In April, 1966, he was no longer making cooing sounds. A check on the medication for seizures was made at this time. Neither the grandmother nor the parents were giving the medication to the baby. Later in the spring, 1966, he was yelling and laughing but did not attempt words. In June of that year, it was observed that he would open his mouth when someone said "bite."

Because of transportation problems, and a lack of motivation and understanding on the part of the parents, the child was not enrolled in the nursery program until March, 1969. At this time, the following

observations were made: walking with minimal support, his feet turned out to his side, making right angles with his legs; he called upon a very light touch of the finger of the supporting person to insure his walking; and it was quite evident that he did not need this for physical support but that he needed it for the security of walking from one place to another. When he was not given support in his walking, he would walk on his knees with the lower half of his legs turned out.

Fine motor skills, at this time, appeared to be much more highly developed than gross motor skills. He was exhibiting a very neat pincer grasp and used this solely in place of any other type of grasp. He was never observed putting anything against his palm of the hand for grasping. He displayed a great interest in fine motor activity such as bead stringing, bean pouring, et cetera. To drink from his juice cup, he was seen placing his two index fingers on the base of the cup and proceeding to drink. He seemed to be functioning at a 1½ to 2½ year level in fine motor skills and functioning at a lower level in gross motor skills. Movements appeared to be quite hypotonic and he was diagnosed as having profound bilateral sensorineural hearing loss.

His verbalizations consisted of some syllables, consonants, crows, and squeals. He seemed quite receptive to gestures and to demonstration. He was able to fit his actions to adjust to directions on a few activities. Some interest was exhibited in feeling vibrations from speech. He seemed to communicate very well with his mother, although they seemed to communicate primarily through gestures rather than spoken language. Expressive language seemed to have developed at approximately

a seven month level. Receptive language skills seemed to be more advanced when gestures accompanied verbalization.

Adaptive Behavior

This boy seems rather compulsive with a series of objects. He tries desperately to keep all the objects in the series together and then pick them up. He is making interesting discriminations, for instance, when he is handed a group of vegetables and fruits to examine, he imediately segregates the cucumber, carrot, and banana from the rest of the items. He is preceiving some very simple similarities in shape, texture, and color. He displays a fantastic memory where things are to be found and where they belong. He usually examines an object by waving it rapidly in front of his eyes before he goes on to see it for purposeful activity.

He loves to roll, spin, and bounce things. He exhibits some self-stimulation mannerisms. These are usually very rapid movements with his hands and fingers in front of his eyes. One hand may be doing the above while the other hand is brushing against his nose and mouth. He seems to be quite hesitant to touch new textures or objects. He may be seen to approach three or four times before actually touching the item.

He does not seem concerned with other children in activities. He relates well to his mother; however, his relation to other adults seems less than specific. His first day in the nursery school, he appeared to be quite reticient to separate from his mother; however, this was not repeated at any other time.

His feeding is improving. The mother reports that he does not chew well but simply swallows. Since he has been in the nursery, he has held his own cookies and feeds himself.

Since the Fall of 1969, we have seen tremendous progress from John. He was seen to walk without support both inside and outside; however, outdoors he is a bit more dependent. John is visually alert and does respond beautifully to demonstration. The first part of this fall we felt that John was not using the materials and activities in a purposeful manner. However, the second half of the year John seems to be quite involved in all the activities and using them very purposefully. John does appear to have some difficulty maintaining a sitting position on the floor; however, he does sit in a chair quite well. We are noticing a good bit of laughing from John and the following sounds: bub-bub-bub-bub-buba, ooooo, and eeeee. Toilet training is progressing very nicely. Some of the activities that John has shown a great deal of proficiency in is pouring colored water, working with the peg board, segregating colors into groups on the Lite-Brite working with all sorts of shapes. He has consistently shown us the ability of matching colors and shapes, but new textures still pose an approach of voidance response from John. John is independently taking out his ear molds when we go for speech training and then places them back in by himself. John is showing some interest in books and pictures, and is turning pages two and three at a time. John showed some resistance to change in routine. Definitely John is attending to factory stimulation; for instance, with corn meal and playdo he smells it first and rejects it even before touching it.

Outdoors John will lead the adult to what he wants to do. He is still resisting finger painting; however, he will paint with a brush.

Again, we have seen tremendous growth since November. His back is beginning to straighten when walking up the stairs and maneuvering the slide is really quite easy for him now. He is showing more interest in people. Purposeful behavior with materials is seen consistently. John doesn't recline to the floor anymore at all. He is beginning to show an interest in musical instruments, a great deal of pleasure in drawing on the chalkboard, does sort out while chalk from colored chalk and will use the colored chalk. He is much more independent in his actions. He is becomming more agressive and has made some gains in moving from a passive child to a bit more of an agressive child. John is peddling the trike by himself. He loves to go through obstacle courses and tunnels. He is responding to amplification on the auditory trainer. John is laughing out loud during the exercises that we do. We are hearing more sounds, pa-pa-pa, ba-ba-ba, up, and many squealing and crowing sounds. We have the feeling that John is really not gaining from his hearing aid. When John brings some material or an object to the preschool, he will never leave without it. He remembers where it is, goes to the object and picks it up. If we should usher him out of the door too quickly he will protest until we bring him back into the room.

Medical Findings

March, 1965; Hernia operation bilateral inguinal herniorrhaphy. Cardiac Catheterization and angiocardiography March 16, 1965. This

hospitalization period was about two weeks.

Catheterization was done in November, 1967. January, 1966, EEG; Paroxysmal slow moderate maximal left hemisphere. Randam simple spike discharges amplitude reduction left temporal lobe region.

January, 1967; Record taken during sleep. Impression; Paroxysmal diffuse simple spike discharges; mildly slow; non-focal.

Cataract repair was done at St. Anthony's Hospital at about 18 months of age. Uses right eye primarily.

CASE: Nan, female

6 months	Sits supported in high chair
6½ months	Sits tripod
7 months	Sits momentarily on floor without support
9 months	Crawls
12 months	Creeps, sole of foot on floor intermitently
12 months	Pulls to stand, stand holding onto furniture
12 months	Imitate sound

Nan was seen in the program beginning the fall of '67. The following are the observations of her.

Primary progress was reported to be in the area of motor development. Nan was seen to be able to walk, climb, and jump. It was felt that Nan could discriminate between objects at a distance of ten feet and was particularly stimulated by light. Her light preoccupation was

thought to be deterrant to her interest in other activities. She was seen also to be preoccupied with rocking her body on the floor. It was felt that an attempt to engage her in specific activity was met with disinterest on her part. The observations that we made in January of '68 was that she was losing interest in her contact with other people. It was felt at this time that Nan had no hearing. She was seen to make throaty noises but no babbling or jargon. Nan can feed herself with finger foods but not with a spoon. She is not toilet trained at this time. Another observational report was made in August of '68. It was felt that Nan had shown no progress since January, and if anything, she had regressed. Her preoccupation with light continued and she overindulged herself in self-stimulating activities such as body rocking, moving hands over eyes, rolling her body over a ball. She made little or no contact with others in the environment which previously had not always been the case. It was felt once Nan became independent in the environment and became mobile that she lost interest in the people in the environment.

Nan began attendance at the preschool again in February, 1969. The following are the observations: Nan was walking independently and exhibiting very good balance. It was very interesting to note that when Nan was given support her body posture seemed to crumble. Occasionally, we would note Nan's body jack knifing. This was interpreted by her mother as a form of resistance; however, many of the behaviors that came after the jack knifing looked very much like seizure behavior. Nan's fine motor movements seemed to be a bit hypotonic. She lifts objects so loosly that she often drops them. Nan demonstrates a

perfect pincer grasp but does not use it functionally. Nan's motor skills at this time appear to be 1½ to 2 years in development.

Language development: Nan did not communicate verbally nor was she responsive to oral language. However, when Nan's hands were placed on the speaker's throat, mouth and cheeks during speech she displayed great interest. Nan makes her needs known by pulling adults and leading them to what she wants. Nan did produce some vowel and consonant sounds. These have been used for stimulus sounds and Nan has repeated them although not consistently, while feeling the articulatory mechanism of the teacher. Nan shows evidence of little interest in mechanical and musical noises. Nan's favorite activity remained throwing objects over her shoulder or over chairs, or under the chair and then retreaving the object. Nan was also quite involved with the light in the room. If there was one square inch of concentrated natural light, Nan would find it and fixate. Her eye-poking is perhaps the most gentle eye-poking I have ever seen. When Nan wears her glasses eye-poking is not as frequent. However, she was seen at that time to poke against her glasses instead of her eyes. Nan was hospitalized for about a month in March. After this hospitalization her behavior was regressive and it was difficult for her to get back into the routine of the preschool again. Nan's vision seemed quite functional. Her arm movements do not always accompany those of her hands. Most of Nan's behavior has been quite passive in structured activities. She has to be greatly encouraged and almost forced to interact or relate to the activity at hand. Nan really is showing a great deal of adaptable behavior, and is much more accepting of new things than are many of the children. Nan thrives on body

contact, especially with her mother, although her mother does not reciprocate the love of this type of contact. Nan recognizes her mother and eagerly approaches her in a group. Nan has displayed little interest in other children except at juice time when she tries to confiscate their juice. She has been seen to examine adults so closely that her eyelashes touch their face. Nan tries to respond in a limited manner to rolling the ball and responds quite overtly to reward.

The following are observations for Fall, 1969 through Spring, 1970. Nan seemed to respond very positively to the increased time she was spending in the preschool program. Nan was seen the first months to explore the room thoroughly and to be willing to be involved in some structured activities like ball rolling, feeling speech, manipulation of various shapes and textures. However, she was not actively involved. About a month later Nan was seen to make tremendous strides almost over night. Nan would seek out activities, would stick with the activity until completion; was not only feeling the teacher's throat and neck during speech but feeling her own and reproducing the mmmmm sound. Body posture changes were very evident. Nan was no longer hesitant to get outside but would go out quite eagerly to swing. She was seen to lame-duck skip around the room and outside. Nan went through a period of licking the chalkboard in our playhouse and the walls. She seemed to fixate on this type of behavior for about two weeks. It was interesting to note at this time she was not exploring any other object orally. However, at a later time she was seen to very much explore objects orally before using them. During the first portion of our fall semester,

Nan was spreading her feces on the walls and on her bed at home. However, this behavior was curtailed.

Nan was rarely seen to chose a prone position or a floor position at all. Light seeking was curtailed significantly. Her involvement with the activities she chose such as the tower building, rolling the ball, working with clay, working with shapes and putting them into holes, building with foam blocks, and working in gross motor activities were some of the things that she would seek out to do. Nan was enjoying the juice period very much and would drink heartily the Kool-Aid that we served. Nan was exhibiting lots of pleasure in the jumping on the spring-a-ling that we have in the playschool. During this time, Nan was seen to reject her glasses often times. However, with some insistence she would keep them on. There seemed to be a change in Nan's behavior around February. The glasses were completely rejected. Nan had an eye exam and a new prescription was provided; however, they have been unable at this time to afford to buy the glasses. Nan became much more passive; her coordination did not seem to be as good; she did want to spend more time on the floor. Nan's eyes appeared to be increasingly clouds and she was still thriving on body contact and feeling speech and enjoying this. Her exploration of the materials and activities involved taking whatever the activity was and lightly taking it all across her body. There seemed to be at this time more oral exploration of objects; then a few weeks later the use of the tongue and the mouth in exploring seemed to decrease but Nan would take the object to her mouth and bite it very, very hard.

During the first week in March, we thought in the preschool that we noted seizure behavior. There was a jack-knifing, a collapse to the floor, the eyes rolled back, one side side of her body was retracted and the other was very much extended rigidly. Since that time Nan has been placed on medication and we have really noticed no significant changes in her behavior. There has been times when Nan has laughed continuously through the whole period for no apparent reason. Nan has, until this month, been afraid of water; however, she now enjoys very much water play and will with a great deal of structure participate in an activity. However, this participation seems to be quite passive and her eyes often seem to be on something else other than the activity at hand. Nan has shown a very great interest in swinging outdoors. She will not hold on if she is swung gently; she likes to be pushed very, very hard and she will keep an upright body position in the swing if you do push her high. I am very concerned about Nan at this time because of this radical change in her behavior and seemingly little carry over from the three month period that we had with Nan of really excelled growth. We have developed a reward system with Nan; she likes to take our hands against her lips and we have saved this for a reward and it has worked quite well in our efforts to get her back into purposeful activity. She has shown an increased interest in the playhouse and will go and explore the playhouse. She will look out the window and find concentrations of light. I have noted that the bald spot on the back of her head is increasing. Nan is still taking her food from the bottle. It is interesting to note that Nan gave up juice drinking when we changed from Kool-aid that was pre-sweetened to sweetening our own Kool-aid.

Nan is showing some interest in musical instruments at this time. As mentioned previously, Nan is thriving on body contact, especially around the chest area and the neck area. There was a time when Nan would come into the room and greet us with her hands out and place them on our neck. I have noticed an increasing cloudiness of her right eye, much mucus formation when she comes in, in the morning.

Medical Findings

EEG May, 1966: Bi-occipital slowing, moderate; random simple spike discharges low voltage; 14/sec. positive spike discharges during speep bi-temporal.

7-4-66: Operation for congenital cataract, left eye. Admitted on 5-23-66 for this surgical procedure.

In February, 1968, a punch procedure - punch excision of pupillary membrane was done on the right eye.

During the May hospitalization, Nan was hospitalized from May thru the middle part of July.

On 2-25-69, Discission, left eye, with control through operating microscope.

March, 1969 - Dehydrated. In the hospital approximately a month. Some kidney infection found by Cardiac Clinic in January, 1967 that Nan has no significant cardio vascular malfunction.

CASE: Zed, male

Seven Months - Mother thinks he hears; cries if door is slammed; looks in the direction of light; laughs when back or abdomen is scratched; cries when diaper is wet; cries when anyone else holds him besides his mother or paternal grandmother; smiles and coos when taking a bath or having his head washed; can roll from prone to supine; catnaps during the day without a good nap; uses fingers to feel face; rubs hand up and will mouth a person's arm if allowed; whimpering sounds but no cooing or gurgling; does not sleep all night; does not have good head control; can't get pacifier to his mouth.

Eight Months - Baby happiest when placed on back on mother's knee with head hanging over; enjoys playing with a rattler; many cooing sounds; can put thumb to mouth to suck; rubs eyes when tired; tries to push self up when put into standing position; prone-pushes self up on hands.

Nine Months - Appears to use right hand more than left; mother notes he attempts to feel things more; cooed while swinging; enjoyed a back carrier; says "Hmmm"; enjoys feeling water in bathtub; doesn't like splashing; knocks at cradle gym; will not grasp it; enjoys sunlight; sleeps through most of the night;

Eleven Months - Appears to know feeding signal; pushes thumb into eye; likes head in unusual position; does better in attempting to pull up; enjoys ringing bell himself; pulling to sit; bears almost all weight.

Twelve Months - Held sitting, rounded back

Twelve-Fourteen Months - Vocalizing

Thirteen Months - Cataract surgery

Fourteen Months - Has not poked eyes since surgery. Since surgery has started putting objects into mouth; making more sounds; enjoys feel of water but not splashing.

Sixteen Months - Still not good head control; most awaking time is spent waving hand in front of face; makes more throat and mouth sounds; laughs aloud; head mostly held up when supported sitting but bobs forward.

Zed was in the Rubella Nursery since August, 1965. The following is a report of the observations: Zed was one of two surviving twins. He would seem to have light perception but does not appear to discriminate between objects. Zed's hearing, based on crying responses, appears to be near the 75 db level for some sounds and he may possibly have an awareness to sounds in the moderate intensity range from 50 to 70 db. No conclusions were drawn from the hearing test.

Zed seemed to progress very little since birth. A great deal of time has been spent in attempting to motivate his mother into following through with a home program of sensory stimulation and motor development. It was felt that Mrs. Doe has been quite lethargic in carrying through with these recommendations. Zed is now sitting with support at a table and will play with objects using his mouth to explore. Zed is a lovable child and enjoys contact with other people. He seldom fusses and seems

content to remain inactive. He does engage in eye poking and moves his glasses to reflect his eyes. This appears to be his only source of stimulation except that imposed upon him by others.

It is not my impression that Zed remained a lovable and easy to take care of child. My recollections are that Zed was frustrated quite easily, was irritable, and that he had a hard time sleeping through the night and that the crying and the care that he was quite difficult.

Summary: (3 years, 7 months): Zed's attendance has been irregular due to difficulty in transportation. During the last three years, training has consisted of attempting to develop the signal system as a basis for communication, development of an enriched home program which includes meaningful sensory stimulation; development of motor skills and counseling for the mother regarding Zed's limited abilities. At this time, Zed's level of communication was very limited. Zed responded to others by smiling, gurgling, and cooing but engaged in little anticipatory behavior. All attempts to develop the signal system failed, due in part to the mother's inconsistent reward system. No symbolic activity or use of imagery has been observed. His overall level of communication has advanced little beyond the level of sensation. Vision was felt to improve with the fitting of glasses; however, Zed is still over-indulgent in light gazing and when not occupied, will remove his glasses, waving them back and forth over his eyes. Zed was aware of perception of movements and could fix on a moving object in tracking. All objects examined visually and tactually are of equal interest and fascination, all being grabbed, mouthed, and handled only briefly. There was seen

to be visual examination of objects but little apparent discrimination. It was felt that Zed has progressed very little in his motor development. He can now sit unaided for short periods of time or with support for longer periods, but does tire easily. Zed can creep but not crawl. Zed returned to the preschool program in February, 1969.

Summary: February, 1969 His gross and fine motor movements were characterized by spasticity. Zed is nonambulatory; however, he does creep using his elbows as an axis grasping hands together, extending hands from midline, then pulling. He is resistant to the prone position and can satisfactorily turn himself to the supine position. Zed can sit in an Indian style fashion, in a kneeling manner, and in a chair at the table. One immediately notes the poor head and neck control. Zed has been noted to lose his balance in a sitting position then to regain balance, which did represent more control on his part. Zed has demonstrated a difficulty really in the ability to release his grasp of objects voluntarily. This was not a consistently observed behavior; there were times when he did relate. It was observed that Zed was more proficient in the left to right arm movements than in vertical arm movements. Zed appears to be functioning at a seven to ten month level in the area of motor development. Physical therapy was administered once per week along with suggestions from the tyerapist for home exercises. Zed's legs remain contracted and the ham strings tight. Zed is nonverbal, but he did express anger and frustration by waving his arms and growling. He expressed pleasure through a very excited, almost uncontrollable laughter. I felt that I consistently saw

responsive touching his diaper when he was wet. Zed's verbalizations are all in the form of crows and squeals which would be appropriate for a four to seven month old child. Zed does respond to loud sounds and the vibration of various noise makers. When hearing aids were taped to their ears and arms restricted, we were able to keep them on approximately 30 seconds. Amplification was received with the same enthusiasm. When the headsets were removed and amplification was turned up and headset held behind head, Zed would attend the sound by sitting very still and cocking his head as if to localize the sound. Zed was functioning as a seven month old child in adaptive behavior. Zed does reach laterally for objects and transfers objects from hand to hand. He ezplores objects orally. However, most of his oral experience with an object is in very rigid, almost unreleasable biting. Zed is able to track objects from left to right if the object is moving very, very slowly. However, he does not track as well when the object moves vertically. Zed was never observed to examine an object at eye level. Zed is quite involved in eye poking activities. When he is sitting and has his glasses on, much less eye poking is observed. However, in the supine position, he will poke constantly if not interupted. We interupted the eye poking by trying to keep Zed's hands busy. Zed tolerates his glasses much more readily than his hearing aid. The longest period of wearing his glasses without removal was 45 minutes. Zed was in an upright sitting position during this period. Zed's chewing was improving a bit; however, the tongue thrust was causing a great deal of difficulty during the feeding time. Zed seemed to be quite involved in table slapping, box slapping, or any other surface slapping.

Whether or not he distinguished between the two different types of vibrations is questionable. He hit the surface of many, many objects with very, very strong blows and it would probably hurt our hands to do this. No paid was noted on Zed's part. Summer time appears to be Zed's season. He loves being outside; they have a swing suspended from their tree and many other interesting materials outside for him. I observed his activity at home and he was seen to play in the water, use the stretch and use his legs much more, and drink very well from a cup outside. Mrs. Doe had constructed a mobile which I suggested, and Zed would reach up and look up for the objects on the mobile. While Zed was in cast, I felt I noted an increased use of the arms and stretching of the arms. Zed commenced out of the preschool program in the fall of 1969. Primarily the changes that were noted was an increased interest in the sitting position, less interest in the creeping. Zed did seem to be quite involved when we would have water play; however, it was mostly splashing. He would join his two hands together and splash. His hands were locked really quite rigidly. One other area that we felt was a new area of exploration was the tambourine. Not only did Zed get to the point where he could hit the tambourine with alternating hands, but he could do it with alternating feet, too, and derived a good deal of pleasure from this. Another significant area of growth was Zed's chewing. Toward the end of Zed's attendance in the program, an improvement in chewing was noted. The tongue thrusting was very, very minimal and he was able to keep the food that he got in his mouth and swallow it. He would eat fresh fruit slices and cookies and things like this

and I felt very strongly that his chewing was much better and he was able to get the mass that he chewed down.

Zed was hospitalized in April for surgery. The surgery procedure was a cutting of the ham string. Zed was put into cast and is now in braces. He is at Convalescent Hospital and will go from Convalescent Hospital to Flake Home and from Flake Home to the institution at Enid. One thing which I would like to note, the eye poking, head banging, and the face slapping really never did decrease. He would keep his glasses on if he had a hood on his head.

Medical Findings

The pulmonary vascularity is probably decreased with a normal heart size and decreased vascularity. One would consider underlying pulmonary stenosis as a possibility.

Hospitalized at one month of age or about the month and five days. Evidently hospitalized for the croup. Zed was also hospitalized for dehydration besides the pneumonitis and great feeding problems and vomiting.

This time, the child was admitted in March of 1965 and discharged in April, 1965.

In May, 1965, a heart catheterization. In February, 1966, cataract operation on the left eye. Cataract surgery on the right eye in February 8, 1966.

September, 1967 - Made new hole through pupil, general anesthetic, surgical procedure.

May 26, 1965 - Moderate EEG report, moderate slowing for age with occasional spike discharges being seen, especially in the left posterior area.

Results of catheterization in May ruled out Patent Ductus Arteriosus but revealed a Coarctation of Right Pulmonary Artery.

April 7, 1970 - Hamstring surgery. When admitted for this surgical procedure, the patient held his knees and hips in an attitude of hyper flexion. Following surgical procedure, the hamstring lengthening, patient was placed in plaster cast and transferred to a Convalescent Hospital.

CASE: Molly, female

11 months	Creeping
10 months	Bearing almost all weight
7 months	Held standing, bouncing
13 months	Walking holding onto furniture
6 months	Head held steady
12½ months	Can go into prone position and change from prone to sitting
13 months	Da-da, Ba-ba
16 months	Two to three words with meaning
16 months	Responding to own name

9½ months	Imitating noises, tries to attract attention by cough
9½ months	Reaching persistently for toy out of reach
11 months	Responding to no
11½ months	Bringing two cubes together
9½ months	Waves bye-bye
6 months	Plays with hand, pulls at clothing
6½ months	Hands to midline, pulls clothing over head in play, overreaches for objects, plays with rattle placed in hand
8½ months	Able to grasp object, plays with toes, objects to mouth, two-hand approach to objects
8½ months	Holds bottle, can't hold objects in both hands simultaneously
12 months	Transfers objects, one hand approach, feeds self cookie or cracker, can hold object in each hand simultaneously
11½ months	Casts object to floor
13 months	One work with meaning imitating sound
11 months	Turns head to sounds

Summary

Severe visual but not hearing loss. At 10 months puts weight on feet only if in walker, does not recognize faces but attends to TV if colored, creeps toward objects, plays bye-bye upon request, uses mouth for exploring, two naps a day and sleeps through night.

At 11 months she pulls up from sitting if someone holds her hand, walks rhythmically if music is loud, appears to be right-handed, rolls from back to stomach, loves red objects, can untie shoes

At 12 months walks on knees, seems afraid of falling, crawled by dragging self along by forearms, middle of this month crawled on all fours, stops activity with certain sounds but can't localize well, on color TV attempt to touch people, upset when grandfather a member of household left on a trip, bangs head.

At 13 months started walking around furniture, recognizes mother and comes to her, selects toy from toy chest, enjoys peek-a-boo, can't sit from crawling position, echolalia, worries when other children cry.

At 13½ months talks to toy horse, ma-ma, da-da, bye-bye, uh-huh, can come from sit to crawling but not crawling to sitting, cruises, babbles constantly, covers ears when sounds are too loud.

At 14 months brings objects close to eyes and studies them carefully, enjoys things and appears to try visual pursuit

At 14½ months had cataract surgery.

At 15 months frightened by the sight of a dog for the first time, studies objects very carefully, disinterested in TV, more head bobbing after surgery than before, feeds dog from high chair, stands on head looking back through legs, loves TV two weeks after above statement, happy, active, noisy.

At 16 months tries to step up onto things, dady, papa, meaningful, attentive to sound with earphones.

At 17 months vision decreasing rapidly, holding fingers between eye and light, cranky, bumps into furniture, leans against TV instead of sitting away to watch

At 18 months still bumps into things, behavior better, can crawl onto sofa, attempting to walk again, now beginning to talk again, loves to rock, not as cautious as before, had learned how to hug neck.

Summary of August 1968: Molly continues to progress but has tapered off in the last six months. Molly at this time presents a picture of a very pleasant child to work with but is still used to having her own way and thus presented a discipline problem at the time. Attention span was noted to be underdeveloped and she preferred to entertain herself for short periods of time with an aluminum coffee pot, some blocks, and beads. Introduction of new material was felt to be difficult; however, if Molly was interested she seems to grasp the concept quickly. Molly's attention span seemed to have increased in the area of practical life exercises such as washing her hands, washing the table. It was felt that there had been very little carryover of attention into other activities. Mention was made of Molly learning her colors, red, blue and yellow; however she was unable to identify these colors if they were not transparent. Head down activities have seemed to decreased. Language continues to progress but at a very slow rate. Expressive vocabulary and grammar appear to be approximately at the 2½ year level.

Molly at this time was 3 years, 7 months. Molly often responds to other language by parroting or repeating what was said. At this time, Mrs. Doe felt that Molly is functioning in the educably retarded range.

Summary of Summer, 1969: Molly was appearing to be quite aggressive motorically to the point where she often times bumped into things. Molly runs and skips in a lame duck fashion. She has mastered steps quite well and uses the alternating foot pattern to go up and down stairs. Balance appears to be quite good. Her sense of laterality also seems to be developing appropriately. This was observed through such exercises as Angels in the Snow. Molly's fine motor skills are developed at a level appropriate for her age except for those skills that necessitate eye-hand coordination for completion. In many instances Molly can compensate for her visual sense. She is now working on buttoning and lacing but has a way to go before mastering these tasks.

Language Development - It is felt that Molly may have suffered from a severe hearing loss during her early years. However, there is no evidence that she is now currently operating under this added handicap. Molly has become a quite verbal child whose speech is characterized by articulation disorders, especially in the plosive and fricative sounds. There is noted to be some hoarseness in her voice or a very hoarse voice quality. Molly is now able to produce the misarticulated sounds in isolation but does not transfer these readily to a word or a word in a sentence. Molly's speech is characterized by many colloquialisms such as "You don't say", "I'll be darned", etc. Molly's vocabulary is appropriate for her age level. She is able to deal with

prepositional directions and expressions. Molly's auditory memory span seems to be a bit short in relation to her other skills in language. Molly in February, 1969, demonstrated a very limited attention span by the conclusion of the nursery. Molly's attention span was considerably increased when she displayed a good deal of pride in completion of activities. Molly is making excellent discrimination in size, shape, and dimensions, and is associating these with her language tasks. Molly is able to count objects up through five and is able to divide the number up into different combinations. For example, give one child three, one child two, etc. Molly exhibits very little skill in synthesizing sounds into words. As would be expected, her ability to analyze a word for its sounds is not yet developed. Molly is quite adaptable to new experiences and activities. A good memory for events is in evidence. However, Molly is still confused as to the time in which they happen. For example, yesterday, today, or tomorrow. Molly is still attempting to examine objects very close to her eye. Molly is quite aware of body parts and relishes the exercises we do to use them. She is beginning to make the distinction between the top of her and the bottom of her, and the right and left sides of her. Molly seems to relish impersonating someone else and would like to continue this type of play for an extended period of time. Molly takes care of her own toileting and washing washing of hands, but brushing her teeth poses a little more difficulty. Molly cannot dress herself completely independently. Molly is eager to relate to other children but seems to feel most comfortable with adults. Molly has found that adults do attend to her as she exhibits behavior that now appears quite clever and cute. However, it

is my feeling that at an older age it may not be as clever and cute. Molly is performing at age level in most areas of development except for the area of eye-motor tasks. She seems to be overcompensating for her blindness. The most striking progress that Molly has made has been in the development of an increased attention span and an interest and willingness to complete activity. She has made great strides in classification of objects as to shape, dimension, and size. Cataract surgery was performed in July, 1969.

Summary of Molly's Performance from September 1969 through January, 1970: In the area of practical life, Molly has almost completely mastered the zipping, buttoning, and buckling frames. She is quite adapt at pouring and managing the table at juice and cookie time. Number concepts seem to be very good up through ten. Although as the numbers get larger there is often times an addition of too many sticks to the associated numeral. Articulation errors are still being heard. However, she has gotten to the point where she can produce them in isolation and with syllables, and with a word upon stimulation. However, in conversational speech we see very little carryover. I remain concerned about any nerve innovation between the velum and the pharynx enclosure in regard to the hoarseness of her voice and the explosive nature of her speech. Extended grammatical structure still seems to give Molly somewhat of a problem. However, I wonder if it is not more a problem in auditory memory than being a problem of being unaware of the grammar. Molly is developing a protective nature about the other children in the class. Each day attention span seems to be increasing. Very little

forgetting is seen. Holly is discriminating between tall, short, thick thin, and discriminating between all the shapes (triangles, circles, squares, and rectangles). Gradation of sizes seems to be easier for her. Her fingertips still seem to be quite sensitive to the messiness of painting and pasting. I am noticing more tactile involvement in the learning about an object than I have before. Holly is not taking an object to her eye as much as she was. She is depending more upon her fingers. Her vocabulary really seems to be above age level; on the Binet Holly tested out at the six-year level. Holly has enjoyed the work to prepare her for braille and the braille work. She, of course, does not seem to be interested in the individual letters and their representation but she does like the representation of a word and does collect these. She has exhibited a good bit of skill with a raised line drawing kit in making different shapes on the paper. This is done with a frame by making up-down marks and left-right marks. In summary, I have been delighted with Molly's progress this fall and the early part of the spring. I have seen her twice since she moved to Tulsa. Retention seems to be 100%. She is very cooperative, very eager to learn. She still appears to be over compensating for her blindness and I notice that she is no longer wearing the glasses that were prescribed to her. It appears as though the parents plan on enrolling Molly in Muskogee School for the Blind in the Fall, 1970. In motor development, Holly appears to be functioning around a 4½ year level although there are some skills that she has incorporated at the 5 year level. In the area of language development Holly seems to be performing at a chronological age of 6 years, although her age is 4 years, 4 months. It is my feeling that receptive language

is functioning perhaps at a higher level than is her expressive language. In the area of adaptive behavior, Molly seems to be performing at a level of 5 years. Her personal social behavior is at an approximate level of 4-5 years.

Medical Findings

On April 13, 1965 she had heart surgery. Open chest surgery. Resection of patent ductus arteriosis.

On April 26, 1965 she had a surgical correction of patent ductus arteriosis. The first surgery was probably for catheterization.

On July 10, 1966 - formation of a proper pupil in each eye and an operation to lower the pressure in the left eye.

On February 22, 1966 she had cardiac catheterization and angiocardiography.

On December 21, 1965 she was admitted to research work for bilateral cataract extraction.

More technically on February 18, 1966 aspiration of cataract, O.D., with iridectomy.

On February 15, 1966 - simple discission of the anterior capsule of the right eye and a discission with aspiration of cataract by push-pull technique and iridectomy, left eye.

On May 2, 1966 - optical iridectomy and possible discission, left eye.

On October 10, 1967-iridectomy and hole punch procedure, left eye.

In April, 1969 - large optical iridectomy, right eye.

On January 21, 1966 - EEG, abnormal slow, mild, irregular and non-focal; random and simple spike discharges.

On April 12, 1965 - Catheterization was discussed

In July, 1969 - Repair or removal of the iris and pupillary membrane, general anesthesia. In July, 1969, also a discission of pupillary membrane, right eye.

ADMINISTRATIVE CONSIDERATIONS FOR IMPLEMENTING PROGRAMS FOR DEAF-BLIND CHILDREN

by

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One thing we must realize is that up until a few short years ago there was nothing really being done for deaf-blind retardates. We had the attitude that nothing could be done for deaf-blind retardates so we spent our money in other places. The theoretical concept of any kind of program development must be considered before the practical application. I think we should discuss the theoretical problems first and then see how the implementation of a program for deaf-blind children fits into this mold. I think we can begin to see that there are some administrative problems. At different levels different people do not feel the same problems. We are faced with how do you change an attitude. Not only at Pinecrest, but how does the nation change its attitude. We are now in the process of changing attitudes. We hope that five years from now there will be many programs for the deaf-blind retardates around the country and that we will be part of the process of bringing that change about.

Normal program development is similar to any learning processes; we must go through several steps. Generally speaking, we must go through five steps. Initially, we must develop knowledge -- what are we talking about. After the acquisition of knowledge we must comprehend this

knowledge. In establishing programs, application is the third level. Analysis is next. After we acquire a program we must begin to analyze it. After that, it will be a while before we can honestly evaluate the program in any indepth way.

In most learning situations people do not get hung up emotionally. One can move easily through these steps and teach a simple fact. But, unfortunately, what has happened in many areas of mental retardation is that problems are approached emotionally, rather than in a congruous way. People become emotional about any changes in programming. When someone becomes emotionally involved because of program change, we hear, "You can't do this.", or "It is very hard to do this.", or "The legislature says its too much money to spend for this.", etc. We are then facing affect. The step by step development of a program that has affect is completely different. To change feelings, you must approach program change very slowly. Initially, the person must be willing to receive information. We must receive ideas. We must respond. We must acquire valued beliefs and we must develop commitment to a new idea. In order to implement a new program there must be commitment to the program. For years everyone has felt you can not serve retarded deaf-blind children. Professional personnel have been saying to parents, "This child is deaf and blind, therefore place him in an institution. There is nothing we can expect except to give him good nursing care." There is some evidence that pediatricians, teachers, and psychologists are changing this attitude. How did this affect commitments? It's pretty obvious. The parent felt there was nothing to

be done and responsible professionals felt there was nothing to be done and so nothing was done.

The program at Pinecrest has undergone the same evolution. The program has started very slowly. Some people around the country began talking about deaf-blind retardates; then some people started collecting material about what is done and later someone discovered there were programs being developed and letters were written and invitations were made. Eventually, Dr. Hammer was invited to discuss deaf-blind programs throughout this region and in the process, all of a sudden someone said, "Let's try a little pilot project. Let's take one employee and a few kids and start something." In the process, we had to make an accurate count of our deaf-blind residents. Mrs. Daniel was very pleased that she now has an accurate count of what we have. As we counted them we began to look at these kids and see what they were doing. So then we had a lot of things going on outside the program. After the kids were counted and their names were being mentioned, someone asked what these children were doing. And slowly more and more people who were involved with the deaf-blind resident began to ask questions. What are we doing for these kids? Is there a little more we might do? And believe it or not, a little more was done for every one of our deaf-blind kids, every one of them. It may have been just a little. Right now we talk about just the three children. Again, it is sometimes very difficult for people to even look at what's going on in their own baliwick, especially if they don't want to look and especially if they are pleased with what they are doing. This happens not only at Pinecrest but all over the country This is a unique thing which happens to people who have set up programs

and all of a sudden they see the program receding. They become emotionally involved and threatened. However, usually as they begin to see things begin to happen, they will respond and try new approaches.

I dare say we have just a handful of people who are committed to working with deaf-blind retardates throughout the United States. The rest of us, and I include myself, are probably at a valuing or belief stage.

Administratively to implement new types of programs one must open the doors. You must allow pilot projects. You must allow experimentation. You must question what you are doing and be open to new ideas. You must be aware of what you have, and that is deaf-blind retardates. We have had them but we really never looked at what they were doing and now at least we have a list of them. We now have the psychology department asking questions and we have a medical specialist following these children and asking questions and talking about them. But even some of these people are going through this process of value change, because if you have a psychologist who believes that you cannot do anything for the deaf-blind retardate, except give him good nursing care, then what are you going to get? You are going to get good nursing care. I am in no way saying that good nursing care is not good for the patient.

Comment from the floor: Well I'm listening but good. I'm the only nurse in here and I hold another opinion.

Answer: I'm saying that - I'm not - Go ahead, I'll let you go first.

Comment from the floor: If you want me to leave I will

Answer: No, no, we want you here

Now here's where I get the affect domain. But, in developing a program one must sometimes actually do things that forces people to respond. Again, all of this has to be done on the surface, around corners, nor directly or too abruptly, because if you take the direct approach you will find that two direct forces repel. You will have a moving away from program development. What you must do is come in, try one thing, sometimes back up, try again, back away and try something else. Sometimes if you must move into program implementation in such a way that you have never really announce a specific goal. If you establish a specific goal in a cognitive area, you have no problems. However, if one has beliefs and commitments to a program in an affective way, you must approach a program change in a completely different manner. Many programs have failed because they did not recognize this fact.

There's one other factor to be considered in implementing program change. This factor is the problem of time, the temporal domain. Program development does not change in a short time. The amount of time required depends on the difficulty of that which you are trying to change. Knowledge is easiest, comprehension next, and application is about in the middle of difficulty. In teaching basic knowledge, to bring this basic knowledge into application takes a very short time in the value of years. But, we are talking about application and it requires time to bring about program application. Often times we go in and say, this is what I learned at the workshop on deaf-blind and I want to apply this tomorrow. You can not apply this tomorrow. You have to take some short steps.

Make sure the people you are working with have time to develop some knowledge and comprehend this knowledge. Then consider application. Very often we see a good idea and we try to begin at the application stage before we are ready. When we do this , the program falls apart. The analysis and evaluation is even more difficult. I have said something about some of the problems in administration.

SUMMARY OF THE WORKSHOP

by

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To summarize the presentations, I would like to review the highlights of each speaker.

Dr. Lent presented the basic theme of the workshop, the utilization of behavior modification techniques with deaf-blind children. He stressed several points which must be kept in mind while working with these children. Perhaps the most important is the necessity of using a systematic approach with these children. In order to ilicit a change in behavior, you must decide what responses you want, analyze each task involved and then break down each task into individual steps. You must constantly evaluate your approach and technique and maintain the flexibility to modify your program if it is not working. Dr. Lent mentioned two problems in working with the post-rubella population of children. The first is defining an appropriate stimulus for these children and the second is utilizing the child's remaining senses. He also mentioned the effectiveness of appropriate punishment in an operant conditioning program. He stressed that one important thing to keep in mind is that the lack of learning is the fault of the program and not the fault of the child.

Following Dr. Lent's presentation, we saw a videotape which included a review of the literature. This tape served as not only a review of the

past theory and research concerning deaf-blind children, but also presented a common body of knowledge from which further planning may be made for program development.

Mrs. Aycock presented case histories of some of the deaf-blind residents of Pinecrest. Relative to Dr. Lent's presentation, she mentioned the difficulty of finding a motivator or reinforcer for these children. This is a common problem we face working with these children. They tend to reject food, touch, odors, and people. Mrs. Aycock mentioned the effectiveness of using light as a motivator and reinforcer.

Dr. Thomas' presentation gave us another approach to behavior modification of deaf-blind children. Certain behavior can be altered by medical intervention. The type and amount of intervention, whether it be by the utilization of drugs or surgical technique, plays a very important role in how the child develops and what types of behavior he exhibits. Her presentation was actually two-fold. She first discussed the children in the Oklahoma City program from the medical standpoint, emphasizing some of the medical problems encountered by the very young post-rubella child. Dr. Thomas mentioned life threatening problems imposed by the heart condition, the commonality of cataracts, and the secondary problems of post surgical glaucoma. In addition, there are other problems related to the nutrition of these children.

The second aspect of Dr. Thomas' presentation concerned itself with the developmental milestones observed in these post-rubella deaf-blind children over a three year period. Paramount among educational problems

is the difficulty of obtaining a valid assessment of these children's hearing and vision. We are finding this to be a common problem faced by professional educators who are working with the post-rubella deaf-blind population throughout the region.

Dr. Dayan discussed some of the administrative problems one might encounter when you initiate a program for deaf-blind children. He discussed some of the problems that have been encountered during the initiation and continuation of the program at Pinecrest. I feel it is wise to be aware of the total implication of initiating any major change in programming or procedures.

Mrs. Aycock then presented us with a demonstration of several of the children with whom she is working.

One thing I noticed is the commonality of problems that have been mentioned by our speakers. The fact that the post-rubella deaf-blind children do not fit into any pre-conceived baseline of standards, either behaviorally, developmentally, or educationally.

A distressing situation that has been mentioned by several speakers is the problem of a general hesitancy among professionals, para-professionals and lay people to attempt to work with these children. People who are experienced with the child are hesitant to work with these children because of their hearing loss. Professionals who work with the deaf say the same thing regarding lack of vision. Educators have little knowledge of these children. Audiologists have no experience with these children.

It appears that many programs are initiated by people who confess to not knowing anything about deaf-blind children.

One thing became apparent during the workshop. This is the fact that once programs are established to serve deaf-blind children, the youngsters do exhibit positive changes in their behavior. It is very encouraging when we talk among ourselves to find you can change behavior of these children

Hopefully with time and workshops like this and as communication is established among professionals, many of the problems we are now encountering will be resolved.

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